Children & Youth with Special Health Care Needs

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CYSHCN Inclusive Language Reference Document

Although there is not a monolithic language style preference shared across all the people who have a disability, it remains important to use respectful and inclusive language when communicating with or talking about people with disabilities.

Foundations:

- Remember that it is possible for two people with the same diagnosis or circumstance to feel completely differently about their disability.
- Transition from assigned genders such as he/she to using the term "They"
- A general rule of thumb is to avoid terms that "connote pity"
- Two major linguistic preferences:
    - **People-first language** "People with disability". Commonly used to reduce dehumanization of disability and CDC recommended. This emphasizes the person first not the disability
        - Ex: A person who uses a wheelchair not wheelchair bound
    - **Identity first language**- "Disabled people". Used to celebrate disability pride and identity (Autistic and Deaf or Hard of Hearing advocacy communities have celebrated this language)
        - Unanimity on which is more respectful, can use interchangeable to acknowledge and respect multiple preferences.
- *Can acknowledge at the beginning of documents of both and speak to which is chosen for the document but validate both perspectives
- Shying away from acknowledgement can reinforce idea of disability as something of shame
    - ***Note**: *The word special is a particularly entrenched because it can be used as a euphemism but also may be utilized technically (e.g., "special education"). There is a desire to move away from this word. However, there is also acknowledgement that terms such as "special needs" are uniquely situated to introduce non-disabled parents and loved ones of children with disabilities to a rich and complex world of disability access, inclusion, accommodation rights, and systems of support*.
- **Do not use language that suggests the lack of something**
- **Emphasize the need for access not the disability**
- **Do not portray people with disabilities as inspirational only because of their disability**
- It is only appropriate to refer to someone as a patient in a medical setting, regardless of their disability status.
    - Not all disabilities are illnesses and not all people with disabilities are patients
- Use "deaf and hard of hearing community" when referring to the community of people with all kinds of hearing loss. Use capitalized "Deaf" when referring to Deaf culture and the community of Deaf people. Use "partial hearing loss" or "partially deaf" for those who have some hearing loss.
    - The term "hearing impaired" is not recommended.

Avoid	Alternative
crazy, mad, psycho, lame	person with mental health condition/illness*
defect, disorder, disease, illness	person with a congenital disability, person living with congenital disability, condition, diagnosis (neutral language)
normal, healthy, able-bodied	non-disabled
condescending language like differently-abled, challenged, handi-capable, etc.	Person with a disability
Handicapped	"person with a disability" or "disabled person"
*Special Needs	Functional needs" is preferred. The term "special" in connection to people with disabilities runs the risk of euphemistically stigmatizing disabled people's differences. The notion is that despite differences in everyone's needs, referring to the needs of only disabled people as "special" carries an infantilizing connotation
High Functioning/Low Functioning	**Significantly impacted*, still considering as a team
Nonverbal	*Does not communicate using oral communication. Use non-speaking.
Suffers from/victim of/stricken with	"they have/are living with muscular dystrophy" is preferred to "they suffer from muscular dystrophy."
Wheelchair-bound	Use "wheelchair user" or "person who uses a wheelchair."
First and foremost, reflect on whether body size needs to be referred to or discussed at all	If weight is not clinically relevant, there is no reason to mention it in discussion or writing • Example: no reason to mention/chart BMI or weight in a patient being seen for strep throat Example: if a patient requires a weight-based dose of medication, stating their weight is necessary, but terms like obesity or overweight are still not useful
Overweight Underweight (These are imprecise and clinically irrelevant terms)	Person at higher weight or lower weight Person in a lager body or smaller body Objectively state the person's weight in pounds or kilograms

Obese Obesity Morbidly Obese Grade_Obesity *(These terms all pathologize a person based on their size alone and are stigmatizing and contribute to bias)* Person with obesity *(This is an example of Person first language (PFL). PFL aims to put the person before the disability and describe what a person has, not who a person is." This makes sense for medical conditions like diabetes, but not for body size.)"*	Higher Weight; Living in a larger body; Person centered language If BMI must be stated use number only, not category (i.e. "BMI of 41," rather than "morbidly obese") Consider asking how the individual self-identifies and their preferred language: • How do you prefer to talk about weight and body size? • What language do you use to talk about your own weight and body size? There are communities using terms like fat, including subcategories like small fat, mid fat, etc. but it should not be assumed that the patient is okay with these terms When referring to body size, PFL still medicalizes/Pathologizes a person based on their size along, which is not supported by evidence and contributes to stigma and bias against larger patients Rather than using PFL, refer to above section
Curvy Fluffy Chunky Heavy Fat	There are other terms such as straight size, mid-size, plus size that are used more often in clothing industry but are less appropriate for a medical setting
Patient is too obese for our MRI/CT/Gowns etc.	Our equipment (whatever it is) is not adequate for patients at this size
Get on the scale please Time to be weighed	If using opt-out weight policy: • Would you like to be weighted today? • Offer blind weigh in an do not state weight without permission Consider an opt-in weight policy: Only ask to weigh patients when specifically needed for their condition (i.e. heart failure, weight-based medication dosing, eating

	disorder treatment). If not required, don't weigh anyone unless requested by patient
Good/bad foods Healthy/ unhealthy foods Junk/processed food Clean/ limited processed foods Convenience foods Cheat foods/ day Indulgent Guilty pleasure Dangerous foods *(Many of these terms are not medically relevant and are taken from diet culture)*	Instead of assigning any moral value to a person's food, behavior, or actions; use neutral language. Try to use terms that reflect specific things about the food being discussed: • More/less nutrient dense • Higher/lower in fat, saturated fat • Higher/ lower in sugar • Higher/lower in salt • Whole fruits and veggies • Whole grains vs refined grains • High/lower in fiber All foods fit: healthy means different thing for all bodies, so no one food is healthy or unhealthy for everyone Food does not have moral value: food choices can impact how your health or how you feel, but food choices do not make you a good/bad person • Treats, sweets, desserts • This food was nourishing to my body while that food was nourishing to my soul
• Healthy and unhealthy food • Bad food and good food • Always, sometimes and anytime foods	• Balanced eating • All foods fit • Avoid labeling foods good/bad • Explore food neutrality
Exercise	Body movement, Physical activity, Joyful movement, Active play
Ther is no consensus on one "best" term to use when referring to a person's size or weight. Some terms are preferred for some people, but not for others considering the origins, histories, and their own experiences with the words. We acknowledge all of these are umbrella terms that lump unique individuals into one group. When possible, we will avoid generalization and use the terminology preference of the individual. When possible, we will ask the person or group which term they prefer.	

Disenfranchised	Participants in life stages that may give rise to vulnerability
Marginalized	People we oppress through policy choices and discourses of racial inferiority
Susceptible	Priority population
Underserved	Structural vulnerability / Structurally vulnerable
Vulnerable	Name the source(s) of vulnerability: bias, cis-hetero domination, discrimination, health inequity, misogyny, oppression, policy, racism, segregation, white supremacy, etc

When Discussing Equity

When referencing disparities, emphasize valuing of equal opportunity for health that reducing disparities contributes to.

Consider:

- Systemic and social inequities-increased risk of illness
- **Avoid implying responsibility** for increased risk of adverse outcomes
- Use social determinants of health for health disparities context
- Consider lack of inclusive infrastructure when considering resource allocation

Key Principals:

Avoid dehumanizing language. **Use person-first language instead**. Describe people as having a condition or circumstance, not being a condition. A case is an instance of disease, not a person. Use patient to refer to someone receiving treatment.

Avoid use of the terms such as vulnerable, marginalized, and high-risk as adjectives. These terms can be stigmatizing. These terms are vague and imply that the condition is inherent to the group rather than the actual causal factors.

Avoid	Alternative
Underserved people; the underserved; hard to reach; the **uninsured**	People who are underserved; people who are medically underserved; people without health insurance; **underrepresented** *Note: "Underserved" relates to lack of access to services, including healthcare. Do not use "underserved" when you really mean "disproportionately affected." Use person-first language.*
Homeless people; the homeless; transient population	People experiencing homelessness; persons experiencing unstable housing/housing insecurity; persons who are not securely housed
Poverty-stricken; the poor; poor people	People with lower incomes; people/households with incomes below the federal poverty level; people with self-reported income in the lowest

	income bracket (if income brackets are defined); people experiencing poverty (do not use "underserved" when meaning low SES) *Note: "People with lower levels of socioeconomic status" should only be used when SES is defined (e.g., when income, education, and occupation are used as a measure of SES).*
High-risk people; high-risk population; vulnerable population; priority populations	People who are at increased/higher risk for [condition]; people who live/work in settings that put them at increased/higher risk of becoming infected or exposed to hazards; populations/groups disproportionately affected by [condition]; populations/groups highly affected by [condition]
Pregnant women; mothers-to-be; expectant mothers	Use terms that are inclusive of all gender identities: Pregnant people; parents-to-be; expectant parents
Rural	People who live in rural/frontier areas; residents/populations of rural areas; rural communities
Referring to people as their race/ethnicity (e.g., Blacks, Hispanics, Latinos, Whites, etc.) • Indian (to refer to American Indian); Eskimo; Oriental; Afro-American; Negro; Caucasian • the [racial/ethnic] community (e.g., the Black community) • non-White (used with or without specifying non-Hispanic)	Preferred terms for specific racial/ethnic groups: • American Indian or Alaska Native persons Asian persons Black or African American persons Hispanic or Latino persons Native Hawaiian or other Pacific Islander persons White persons People who identify with more than one race/ethnicity; people of more than one race/ethnicity *Note: Black and White should be capitalized. Note: "American Indian or Alaska Native" should only be used to describe persons with different tribal affiliations. Otherwise, identify persons or groups by their specific tribal affiliation.* Preferred terms for groups including 2 or more racial/ethnic groups: • People from some racial and ethnic minority groups • People/communities of color Note: Only used to collectively refer to racial and ethnic groups other than non-Hispanic White; be mindful to refer to a specific racial/ethnic group(s) instead of this collective term when the burden and experience of disease is different across groups.

References

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